Missouri Department of Mental Health
Division of Mental Retardation
and Developmental Disabilities
Revised – September 16, 2003
DRAFT

Under Construction:

"System Breakthrough for Excellence Report"

Draft Report to Steering Committee
August 2003

TABLE OF CONTENTS

Page

OPENING COMMENTS FROM THE DIRECTOR:

Please read this draft report as far more than the Director of the Division of Mental Retardation and Developmental Disabilities' response to many insightful and important recommendations that resulted from the System Breakthrough for Excellence project involving a wide range of consumers and families and stakeholders across Missouri. This report is, above all, a glowing testimony to the goodwill and partnership that all of these persons demonstrated as they gave so willingly of their time and energy.

Through many meetings and countless hours of thoughtful discussion, participants at every phase of this project considered complex issues and concerns about the adequacy and effectiveness of the Division's service delivery system, policies, and programs. They did so within a process framework designed to identify changes needed to make a demonstrative difference in the lives of persons with mental retardation and developmental disabilities whom we support today and those whose needs in the future might be different. The best tribute to their work will be the extent to which it will result in positive systems change, an outcome to which I am totally committed.

This draft report is organized to enable the Steering Committee members to:

1. Review the most important information first: those recommendations which the Division accepts and is prepared to move upon.

   Given limited resources, Division staff and I focused on recommendations which:
   a) had the power to change things system-wide and also affect more specific recommendations;
   b) appeared "doable" over the next one to three years; and
   c) support the Department's core values.

All recommendations will be revisited on a quarterly basis to ensure that they are being acted upon as quickly as resources and opportunities permit.

2. Have enough information at hand at the August 26, 2003 meeting to consider the "goodness" of the Division's responses and give their support and/or suggest changes/additions to the Division's responses with the goal of finalizing the report.

3. Recommend the content and format for this report which will be posted on the DMH web site and presented in other venues for public comment, with a deadline date for those public comments.

A number of appendices to the report provide important context and background:

1. A listing of all recommendations from the Work Groups.

2. The purpose for the Systems Breakthrough for Excellence project and the initial charge of the Division Director to the Steering Committee, otherwise known as the Team Charter.

3. The process used for the Systems Breakthrough for Excellence Project under the guidance of the office for Missouri Results Initiative staff. For example:
    a) A list of Steering Committee members;
    b) Number of focus groups involving segment specific groups of consumers;
    c) Nature, purpose, and membership of work groups.

4. Population data and other data pertinent to recommendations and responses.

5. Map of Missouri, with location of Regional Centers and Habilitation Centers

6. Referral sources and points of entry to the Division of Mental Retardation and Developmental Disabilities service delivery system.

7. Special Issues to Consider: Waiting Lists, Consumer Support Waiver Approval, Caseload Growth Funding, and Administrative Consolidations

8. Acknowledgement of contributors

The Systems Breakthrough for Excellence project and this report come at a crucial time. As demand for services increases, the current economic climate limits the Division and its partners' capacity to serve all persons with mental retardation or other developmental disabilities that would benefit from support. There are an estimated 100,714 individuals in Missouri with developmental disabilities (based on Missouri population of 5,595,211). Approximately one to two percent (1-2%) of Missouri's 75,000 new babies each year are born with some form of a developmental disability.

In Fiscal Year 2003, the Division provided services and support to 31,000 Missourians. Are they the Missourians in greatest need? Are their needs being well-served? What's working, what needs to be done better, what do we need to try, what do we need to quit doing? I am indebted to the recommendations in this report which will help answer these questions and support the desire and will of all MRDD staff to create a new service road map that will best serve those in need of Division of MRDD services and supports, while embodying the Department's core values of:

- Easy Access
- Self-Determination
- Caring, Competent and Valued Staff
- Community Integration
- Prevention and Early Intervention

With deep appreciation for the work accomplished to date and with enthusiasm and commitment for the good work before us, this draft report is for your review.

Anne S. Deaton, Ed.D, Director
Division of Mental Retardation and Developmental Disabilities

SECTION ONE: WORK GROUP RECOMMENDATIONS:

A total of sixty-two (62) recommendations were produced by eight consumer specific work groups (see Section Three: Segment Specific Recommendations). In an exercise to organize these recommendations in a meaningful way, work group and Steering Committee members, at a meeting held on April 29-30, 2003, identified seven (7) common themes reflected across the eight (8) consumer segment specific work groups. These common themes are:

1) Improve access to information;
2) Make funding equitable geographically and among consumers with like needs;
3) Better collaborate with the community to provide services;
4) Give consumers choice/control over resources;
5) Earlier identification of risk factors in children;
6) Reduce the administrative burden for staff and consumers to get services;
7) Improve skills/competency training for staff.

At the April meeting, these seven common themes were further reduced to the top three "system-wide" issues. The "system-wide" issues identified are:

1. Improve Access to Services through Collaboration;
2. Increase Consumer Choice and Control;
3. Enhance Competence and Information

Fifty-four (54) of the sixty-two (62) recommendations were clustered under one of the above system-wide issues. Generally speaking, a recommendation was considered "system-wide" if its adoption and successful implementation not only improves the circumstances to which it directly speaks, but also changes for the better other components of the service delivery system. An additional eight recommendations stand separately as consumer segment specific issues.

After considering these recommendations with appropriate staff, I am reporting to the Steering that the

GOALS/INTENT OF ALL 62 RECOMMENDATIONS ARE ACCEPTED BY THE DIVISION.

Final acceptance by the Director of the Department of Mental Health, feedback from the Mental Health Commission and other key stakeholders, such as the Missouri Planning Council and the Regional Advisory Councils, is now sought.

Clearly, not all recommendations can be activated immediately or simultaneously. Some are long-range and require changes to systems or legislation external to the Division and the other recommendations, in their present form, do not include specifics about how they could be implemented. That will be the responsibility of task groups. The important point is that the intent of these recommendations provides clear direction for systems change.

All these realities accepted, the Division is prepared to begin.

The first step, already taken, was to prioritize which recommendations would be highlighted in this report for immediate action and proposed initiatives. Prioritizing involved selecting those recommendations that:

1. Impact "system-wide";
2. Are "doable" over the next one to three years because of existing resources or the opportunity to access resources;
3. Support and advance the Department's values.

Using this approach to prioritize recommendations meant, by definition, that this draft report would not focus in-depth on the eight (8) segment specific recommendations. Still important information, though presented in brief in this report, is provided in response to these eight recommendations in terms of proposed action steps. Indeed, some of these action steps are already underway.

While the proposed initiatives included in this report are priority action steps, the Division will carefully track, and provide up-date reports on, information related to the advancement of all the initiatives through the DMH web site.

Please refer to Appendices D and E for a complete listing of all recommendations, both system-wide and segment specific.

Section Two of this report identifies proposed initiatives that address a select number of "system-wide" issues and recommendations. Some initiatives address multiple system-wide recommendations and some segment specific recommendations. Each initiative described is linked to the appropriate recommendations. There is also a summary chart of the initiatives, including a very brief outline of any action plan to the extent it is available at the time of this report.

SECTION TWO: SYSTEM-WIDE RECOMMENDATIONS AND INITIATIVES:

The Division of Mental Retardation and Developmental Disabilities Executive Team reviewed the recommendations made by the Steering Committee from the work done by the work groups. In response, the Division is making a commitment to proceed immediately on the initiatives listed below. A summary of all recommendations made by the work groups is included in the Appendix D.

1. Individual Budgets for Consumers
2. Statewide Rollout of System of Care Model
3. Standardize Formula for Size and Composition of Caseloads
4. Service Coordinator Competencies and Training
5. Stabilization Unit
6. Access to Information in Easy to Read Format, through Internet
7. Direct Care Worker Competencies and Training
8. Partners in Employment Project
9. Family and Consumer Support
10. Study Possibility of Expansion of Crisis System
11. Development of Performance Measures

NOTE: Each of the initiatives explained below will be implemented in response to the System-Wide Recommendations. Each initiative is described and a key included that ties the initiative to recommendations made by the Steering Committee. This is shown in parenthesis ( ). Also included is a summary of all the Proposed Initiatives tied to the System-Wide Recommendations.

1. Individual Budgets for Consumers
(Access, Consumer Choice and Control):

a. Improved access for all persons to their budget using a web-based system and pilot sites for individuals in conjunction with the Independence Plus Grant.

This initiative's goal will result in a self-directing budget process, a service delivery approach that combines the principles of individual choice, control, and independence with personal decision-making and responsibility.

The Division of MRDD has applied for an *Independence Plus* grant from the Centers for Medicare and Medicaid Services (CMS). If funded, this grant opportunity will allow the Division to make changes in its system so that it is prepared to implement self-directed support options associated within the Independence Plus model. Even if the Division does not receive the *Independence Plus* grant, the Division is committed to following through on this initiative. The following objectives are planned:

(1) A Missouri Self-Directed Planning Task Force to review the current system and plan for enhancing self-direction within Missouri's long-term care service delivery system.

(2) The following components will be part of this system:

   (a) Person-Centered Planning: A participant directed, person-centered planning system will be implemented that uses brokers outside of the system or service coordinators with no gate-keeping responsibilities.
   (b) Missouri Community Advocacy Network (MOCAN) volunteers will conduct training for consumers and families on how to manage and self-direct supports.
   (c) Ways in which individual budgets and self-directed can be controlled by service participants, and be used to bring funding from different agencies together in a more efficient manner will be explored.
   (d) The use of a more flexible fiscal intermediary system will be explored as well as the possible use of debit cards and a mechanism so that individuals can check their authorization balances at any time (possibly in a web-based system).
   (e) A participant-directed support brokering system will be implemented.
   (f) The current statewide emergency backup system and incident management system will be reviewed and adjusted to interface with this self-directed system.

(3) A pilot incorporating the various aspects associated with self-directed support systems will be conducted with individuals with disabilities and/or their families. An extensive evaluation of cost effectiveness, quality of life, abuse/neglect, retention of personal care assistants, etc. will be an essential part of the pilot.

Timeline: Grant Period: October 1, 2003 – September 30, 2006
Pilot Project: October 1, 2004 – September 30, 2006

Comments from Focus Group Members:

"Give us access to plans 24 hours a day."
"Provide a list of individuals who provide services that families can contact themselves."
"Make it easy for people to know where to go for services, can find services that meet their needs, and can do so in a timely manner."
"We want to make decisions about what happens to us."
"Be able to transfer service and dollars no matter where families move within the state."

Pursuant to direction of Steering Committee members, the Division of MRDD will create a "backup" plan to address the implementation of this recommendation without benefit of the Independence Plus grant. This may include formation of a team of people committed to system change to develop a proposal to mirror the pilot and objectives in the grant.

2. Statewide Rollout of System of Care Model
(Access to Specialized Services, Collaboration, Improved Transition for Youth):

A. Children with the most complex needs are frequently placed in costly out-of-home placement; they often experience multiple placements by multiple agencies; they are often failing at school and they are frequently involved with the juvenile justice system. No one agency has the ability and/or resources to adequately meet the multiple needs of these children. For services to be effective and cost efficient, they must be provided within a "System of Care" that unites planning and funding from all child-serving agencies.

   While the Department of Mental Health has taken the lead on this initiative in piloting this concept in 5 areas of the state, it is fully supported by the Division of Youth Services, the Division of Family Services, the Department of Elementary and Secondary Education, and the Office of State Court Administrators. Because of the complexities, as well as the number of agencies involved, the implementation of the System of Care model statewide will require effective evaluation and enhancement in the pilot areas. The pilots presently represent both urban and rural areas and the successes and challenges in all of the pilots will be taken into consideration when a proposal to roll out the program statewide comes forward. The Department's values listed above and references throughout this document will be taken into full consideration.

Timeline: Full implementation and evaluation of the pilot areas by June 2004, with state wide implementation anticipated within 1 to 3 years following.

B. DMH applied for Community-Based Treatment Alternatives for Children (CTAC) grant from Center for Medicare and Medicaid Services (CMS). If awarded funding, the project will conduct a feasibility study, and develop an implementation and evaluation plan which will assist Missouri in designing and developing a comprehensive system of community-based services and supports for children with diagnosis of serious emotionally disturbed, including those who also have mental retardation and/or a developmental disability, and otherwise require care in a psychiatric residential facility. Missouri's goal is to expand services that will enable a child to stay in their home and organize those services in a comprehensive system that will
   1) provide an effective "single point of entry" regardless of how the child first contacts the system;
   2) provide a continuum of effective services; and
   3) blend disparate funding streams to support the system.

Timeline: Grant Period October, 1, 2003 – September 30, 2006

Part of the proposed pilots in the Independence Plus grant application will allow the Division of Mental Retardation and Developmental Disabilities to explore the feasibility of individuals having a single plan of care when multiple agencies are involved and blended funding for services.

Timeline: October 1, 2004 – September 30, 2006

Comments from Focus Group Members:

"Create a unified document for all agencies such as regional centers, VR, schools, DFS – a generic application for services."

"Have one service plan that will accomplish overall needs, and then hold each other accountable."

"Good communication between all agencies and families."

3. **Standardize Formula for Size and Composition of Caseloads**
   (Access to Service Coordination, Specialized Service Coordinators, Reducing Caseloads, Enhanced Competence of Staff):

   A. This initiative will be undertaken by the newly formed Caseload Management Advisory Team (MAT), which will be comprised of both Union members (case managers), as well as Division supervisory staff.

      Timeline: October 1, 2003-October 1, 2004

Comments from Focus Group Members:

"Be there when we need you."

"Gain an awareness of how to respond knowledgeably – well trained service coordinators and adequate funding."

4. **Service Coordinator Competencies and Training**
   (Collaboration, Access to Service Coordination, Enhance Competencies and Information)

   A. Case management manual completed and available online.
      MRDD Case Managers are considered the Regional Center's "front-line" staff, and are involved in nearly every aspect of habilitation efforts completed on behalf of individuals the Division supports. A "how-to" manual has been developed by a management advisory team, finalized by the Division's Executive Team and distributed to all Regional Centers, as well as being placed on the DMH intranet for all staff to utilize. Now that the manual is complete and in place, the Division will implement a system designed to ensure the manual is current and accurate.

      Timeline: This is ongoing

   B. Development of standardized training for case management supervisor staff – Case Manager Supervisors are key individuals in dealing with issues and facilitating proactive activities in Regional Centers. A comprehensive standardized training package for supervisors must include not only the "how-to's" that Case Managers must know, but also supervisory skills, coaching skills, administrative skills, and cultural competencies.. They also must be knowledgeable of system-wide issues and trends that they may encounter. A number of sources exist from which information gathering will be necessary. Some of these include the Department of Mental Health's Office of Quality Management, the Department's Personnel Office, the Division's Section of Quality Improvement and the Department's Office of Multi-Cultural Affairs, as well as the data highlighting concerns and suggestions for future direction gathered from the focus groups

in the early stages of this initiative. Information gathered from these sources will be synthesized with ongoing information collection from the Regional Centers and Habilitation Centers, in order to determine the critical areas requiring standardized training for supervisory staff.

Timeline: Analysis and synthesis of data by November 2003. Initial development and piloting of training, including seeking stakeholder feedback; and role-out of standardized training by November 2004.

C. Use of Tools Such as Project Safeguard and Service Coordinator Monitoring Tool -- The Division has designed and is implementing a "Framework for Consumer Safeguards and Quality Outcomes" (statewide QA/QI Plan). The system design currently includes eight (8) quality management functions that involve multiple "real-time" methods to gather information concerning all aspects of the MRDD service delivery system. Each function has its own process for discovery of needs/issues/concerns; action planning for remediation of problems and data analysis and trending for systems improvement. Six (6) of the eight functions (service monitoring, personal plan audits, health inventory and nursing audits, fiscal audits, consumer and family quality assurance visits and mortality reviews) are being implemented division-wide. Two (2) of the functions, Licensing & Certification and Incident Response, are department-wide functions.

   The design of the Personal Plan Audit function (underdevelopment) includes training for service coordinators to increase their competencies regarding person centered planning. The Division will revise and expand the October 2000 "Person-Centered Planning and Home and Community Based Waiver Guidelines" document for statewide implementation with all service coordinators and community contract providers serving persons through the MRDD delivery system. The Guidelines, as written, include a section called "Vision for the Future" which addresses the Systems Breakthrough recommendation to include a section in the personal plan to forecast and plan for future needs.

   All service coordinators, other appropriate regional center staff and provider staff will be trained on the person-centered planning guidelines. As part of the Division's "Framework for Consumer Safeguards and Quality Outcomes" (statewide QA/QI Plan), it will design a quality assurance system to determine if personal plans are effectively addressing the needs, preferences, goals (including a future needs) according to the Person-Centered Guidelines and the Division's Quality Outcomes document.

   In addition, service coordinators and other appropriate staff will continue to receive training on the Service Monitoring tool designed for use during routine visits with individuals. Service Monitoring is one of the eight (8) division-wide quality management functions to promote effective services and supports on behalf of individuals and to assure their health and welfare.

   Timeline: Personal Plan—2004. Services Monitor implement, June, 2003. All procedures of Project Safeguard in place by July, 2004.

Comments from Focus Group Members:
"Same rules/regulations for all regional centers."
"Competent people to do the work. Hold people accountable for their work, and let people go who don't now their job."
"Staff are caring, competent and valued employees."

NOTE: Initiatives #3 and #4 will be tied closely and the Caseload Management Advisory Team will be kept updated on activities under Project Safeguard.

5. **Stabilization Units**
(Access, Collaboration)

A. Stabilization Unit for Youth at Bellefontaine Habilitation Center – A unit is being developed at Bellefontaine Habilitation Center to work with adolescents. This unit's purpose is to give adolescents with behavioral issues an environment that addresses their behavior in a therapeutic environment. The goal of the unit is to stabilize the person for a successful transition back to the community as agreed upon by the family member or guardian.

Timeline: Current and ongoing

B. Stabilization Units for Adults – The Division of Mental Retardation and Developmental Disabilities habilitation centers can enhance their ability to provide supports to Regional Centers and community living arrangements by establishing and operating short term stabilization units.

Such a unit could provide a secure setting with specially trained staff to provide crisis support, medication review and positive behavior supports. A secure setting would ensure that others living in the center would not be endangered. The purpose of the unit is to stabilize the individual so that he/she can return home or to their community living arrangement safely, with individualized supports, as quickly as possible.

Although all admissions to habilitation centers are considered short term, admission would be on an individual basis and could be anything from one day to six months. Division Directive 4.040—Referrals to State Operated Habilitation Centers—would apply to this initiative.

These units would be created using existing structure and without adding to the habilitation center's census.

The Division recognizes the limited availability of this specialized service. Not all families or people will choose to use these services in the limited locations available.

Timeline: This involves a transition of individuals into the community, development of community resources, and may take up to nine months to complete. This process has now begun at Bellefontaine Habilitation Center.

Comments from Focus Group Members:

"Services must be delivered in a fashion that respects the urgency people feel."
"Immediate response – behavior person who can respond quickly."

6. <u>Access to Information in Easy To Read Format, through Internet</u>
(Access, Collaboration, Streamlining Forms and Procedures, Consumer Choice and Control):

A. Information on licensure and certification of providers to be posted on DMH web site. The Division will work with the office of Quality Management, Licensure and Certification Unit, to determine the feasibility of providing through the DMH Internet website the most recent survey reports of providers licensed/certified by the Department of Mental Health. The Division will learn from the regulation that the Department of Health and Senior Services will implement August, 2003 that pertains to the posting of the most recent survey of every home health agency and any deficiencies. The website will include the agency's proposed plan of correction.

Timeline: Determine feasibility by December 31, 2003

B. Information on abuse/neglect reports and grievances to be posted on DMH web site:

Quality Assurance/Quality Improvement Grant: The Department of Health and Senior Services submitted a proposal for a Quality Assurance/Quality Improvement Home and Community-Based Service Grant from Center for Medicaid and Medicare Services (CMS). If funded, the Division of MRDD will be a partner. The overall objective of this project is to ensure the health and safety of persons who live in the community and receive services from any of the seven Medicaid waivers the State of Missouri operates. (The Division of MRDD oversees three of the seven).

State agencies that administer these waivers and the state Medicaid agency will identify common data elements and a web-based system that all agencies can access will be designed. Data collected through service coordination monitoring, personal plan audits, health inventories and nursing audits, consumer and family member quality assurance visits, fiscal audits, mortality reviews and certification surveys that impacts health and safety will be input. Also complaints will be tracked. Utilizing the information from the data base will assist the state in identifying where prompt system changes are needed to enhance consumer outcomes.

C. Community Connections: Web site presently kept updated by the University of Missouri Extension Service. Includes information from local communities, including programs, providers of services, and links to appropriate resources. Division will participate by providing links to this web site, as well as providing information on our services to this web site for posting. Providers will be encouraged to do so as well.

Timeline: Grant Period: October 1, 2003 – September 30, 2006
Web-site development: October 1, 2005 – September 30, 2006

<u>Comments from Focus Group Members:</u>
"Give us access to plans 24 hours a day."
"Give us timely, accurate information."

"Reduce the red tape of the system, and reduce paperwork."

Pursuant to direction of Steering Committee members, the Division of MRDD will create a "backup" plan to address the implementation of this recommendation without benefit of the Independence Plus grant. This may include formation of a team of people committed to system change to develop a proposal to mirror the pilot and objectives in the grant.

7. <u>Direct Care Worker Competencies and Training</u>
(Collaboration, Enhance Competencies and Information)

A. Implementation of Workplace Improvement Recommendations (i.e., standardized training package for direct care staff and supervisors, etc.) The Division proposes to create a competency-based system for direct care staff, case management staff, and supervisory staff. Four components are to be included in this process:
   1. Formal – Classroom/Test (including computer based learning)
   2. Hands-on Application – demonstration of abilities
   3. Individual on-site professional clinical mentoring
   4. Continuing Competency

   Timelines:

   1. *Inform all stakeholders of MRDD/s intent in this area – 1 month*
   2. *Identify available resources – 2 months*
   3. *Develop cooperative agreements with other state agencies – 2 months*
   4. *Identify best practices for curriculum development – 3 months*
   5. *Working session of stakeholders to customize components needed in training package to include review of diversity-based elements – 3 months*
   6. *Develop curriculum and choose delivery method – 6 months*
   7. *Pilot and refine curriculum – 6 months following step number 6*

B. Community Direct Care Worker Grant Application, in collaboration with UMKC and other Divisions

   DMH, in partnership with University Center for Excellence, the Missouri Planning Council, and Independent Living Centers have submitted an application for a Community Direct Service Workers Demonstration Grant from the Centers for Medicare and Medicaid Services (CMS). The purpose of the project will be to improve the ability of individuals and providers to recruit and retain community direct care staff.

   If funded, the core components of this project will be
   1) create statewide access to a number of health options and market availability;
   2) develop direct support professionals credentialing system and mechanisms to deliver the training (e.g. community colleges, internet);
   3) develop and deliver an organizational mentoring and training program to organizations within pilot communities;
   4) pilot a voucher system in select rural areas for the purchase of transportation and/or child care; and

5) develop comprehensive community partnerships to support piloting grant initiatives and replication efforts.

Timeline: Grant Period: September 30, 2003 – September 29, 2006

Comments from Focus Group Members:
"Competent people to do the work. Hold people accountable for their work and let people go who don't know their job."
"Having and applying guidelines uniformly."
"Staff are caring, competent and valued employees."

Pursuant to direction of Steering Committee members, the Division of MRDD will create a "backup" plan to address the implementation of this recommendation without benefit of the Independence Plus grant. This may include formation of a team of people committed to system change to develop a proposal to mirror the pilot and objectives in the grant.

8. Partners in Employment Project
(Access, Collaboration, Consumer Control, Person Centered Planning)

This initiative will focus on supporting and tracking pilots (outlined below) that offer great promise for readying individuals for supported or competitive employment. They will include collaboration on both the state agency and community level. The Division recognizes, however, that these initiatives do not reflect the ONLY mechanisms for supporting persons with developmental disabilities and employment. The Department's values speak of community integration and self-determination, which includes striving for a "living wage". These values will all be considered as the Division moves forward to evaluate these initiatives:

A. Public Entity Role Models: Regional Center and Habilitation Center

Regional Center - Presently a number of regional centers provide employment for consumers with varying skills. The regional centers will continue offering employment opportunities as available and appropriate. In addition, if identified in the consumer's support plan, the employment phase at the regional center will be considered an "internship." Alternative or additional employment opportunities will be sought and supported in the community. The Hannibal and Kirksville Regional Centers will track the number of consumers employed and the number of consumers who complete internships that result in alternative or additional supported employment opportunities.

Timeline: Present to October, 2005.

Habilitation Center - Most Habilitation Centers already have some type of vocational training program and utilize on-campus work activity centers to accustom the individuals to engaging in some type of meaningful vocational tasks. The people who work in these centers get paid for their work.

Vocational training will be expanded on a pilot basis:

1. Individuals could take on tasks formerly performed by state workers, for instance, custodial, mailroom or clerical work. This job could be an end in itself or could be used as a training program for custodial work outside the facilities.

2. Individuals living in the community, but not yet ready for gainful employment, could participate in vocational training in the Habilitation Center's day programs, as a training ground to other supported or independent employment. Providers would need to provide job trainers or staff escorts for those coming back during the day.

Timeline: Present to October, 2005.

The reference to "role model" is descriptive of the intent of the Division of MRDD to provide employment opportunities as available and desired by consumers. These opportunities at the regional centers and habilitation centers represent the Division's commitment to employment. It is not intended to limit job opportunities for people who seek them and find them with other employers.

Comments from focus group members:

"Create a unified document for all agencies such as regional centers, VR, schools, DFS—a generic application for services."

"Allow the money to follow the person versus the agency following the money, and then the person."

B. Collaboration Models:

The Senate Bill 40 County Boards of Lawrence and Barry Counties co-funded an employment coordinator position, utilizing the Association of Retarded Citizens of the Ozarks as the lead agency. Individuals identified as having needs related to employment by the Joplin Regional Center are referred to the employment coordinator. The coordinator, by networking with employers in the area, works to find employment options for these individuals.

The Lawrence County Senate Bill 40 Board has enlisted the expertise of the Institute of Human Development at the University of Missouri-Kansas City to work with Joplin Regional Center to focus on multiple strategies that may be needed to advance an individual toward successful employment and job retention. Some of the strategies designed to achieve this goal include:

a. interest inventories;
b. brainstorming discussions;
c. development of action planning for investigation into and eventual procurement of employment

Follow along funding may be available through the Regional Center, depending upon needs identified in individual support plans.

Timeline: As these are both relatively new initiatives, the Division will continue to pilot both of these activities in conjunction with the SB 40 Boards to determine whether they can be

replicated statewide. Evaluation of the effectiveness of these activities will commence January, 2004.

C. Missouri Career Network --Proposed Partnership with Department of Mental Health, Division of MR/DD

Missouri Career Network is a 5-year demonstration project funded by Rehabilitation Services Administration (RSA). As of September 2003 we are quickly approaching the end of our 3rd year. This project was designed and developed through a team of individuals from the Institute for Human Development (A University Center on Excellence) at the University of Missouri—KC, at the (University of Missouri—Columbia), and state/national-consultants.

It is our belief that many variables contribute to a lack of progress in further advancing community employment for people with significant disabilities. These include the lack of shared values and beliefs that community employment is possible for all people, the lack of control over funding and resources by people with disabilities, and the absence of comprehensive grassroots community initiatives that address change for the person, organizations, systems, and the community at large.

The statewide initiative is attempting to promote change at three levels:

1. Change at the Individual Level: The person will have a job and career (including self-employment) that is meaningful to and consistent with his or her preferences, interests, and talents;;
2. Change within Organizations and Systems: Organizations and systems will align policies, procedures and resources to support community employment; and
3. Community change: Effect change in the capacity of communities to better support careers for all citizens, including citizens with disabilities.

The MCN initiative's principle guiding belief is that all people who want to work can work, and it is the responsibility of the person and his or her personal network of supports to make that become a reality. Personal networks can be divided into two categories: formal and informal. Formal networks consist of professionals, such as service coordinators, teachers, school counselors, VR counselors, and so forth. Informal networks consist of family members, friends, and other community members.

Kansas City Pilot Project
Timeline: (November 2002 to present)
Our partnership efforts within the Kansas City area have been an organizational /system specific focus since November 2002. A focus group was formed and has evolved into a pilot project with Vocational Rehabilitation, Department of Mental Health MR/DD, areas service providers, and 3 local school district representatives.

Next Steps:
This group agreed to start small and focus on 5 school districts to target and hold an awareness workshop. This group would also include VR counselors, providers and DMH

folks as appropriate. Students and Family members will be invited to the second awareness workshop. This strategy was developed with the idea that teachers, providers, counselor would be better equipped to answer questions if they knew more about the project first. The awareness workshop is scheduled for April 4, 2003, at UMKC Admin. Building 10:30am to 2:00pm with lunch provided.

The five school districts identified are:

1. Kansas City Missouri
2. Raytown
3. Center
4. Blue Springs
5. Independence

Proposed Partnership with DMH (based on focus group recommendations):
MCN feels our project focus fits very nicely with the departments focus for young adults transitioning from high school. After reviewing the results from the focus groups held by the Division of MR/DD, we feel that MCN efforts match well with the recommendations offered by the this group.

The recommendations from the DMH focus groups were;

1. Develop a training curriculum for all individuals involved in the transition process.
2. Have one Person Centered Plan used by all agencies supporting the consumer.
3. Develop outcome-based reimbursement system empowering families and consumers to direct their own supports.
4. Make transportation more available to consumers by collaborating with other agencies.
5. Use the consumer information database to create a monthly report that identifies when individuals turn 14 resulting in earlier intervention.

How to make it happen:
Conduct a three to five year pilot to work on these recommendations concurrently. This method will help to build collaborative partnerships between stakeholders, promote sharing of responsibility, accountability, and allocation of joint resources, encourage early and proactive planning, and allow for a trial period to refine the process prior to statewide implementation.

Timeline: Present to July, 2006

a. Innovative Use of Personal Assistance Workers – There is an increasing need for employment options for people with disabilities, and a need for more cost efficient alternatives. The use of personal assistance workers through employers, residential and other service providers, along with utilization of fiscal intermediaries that allow individuals to hire their own supports, provide a less restrictive and more cost effective alternative as supports for individuals with disabilities seeking employment.

   Several versions of this general concept have been utilized in some areas of the state. In Sedalia, as in Carthage, a group home provided a personal assistant to serve as a coach for an individual to locate, obtain, and become proficient in his employment.

In Joplin, the Regional Center contracted with an employment agency to locate job opportunities. Then, utilizing a fiscal intermediary, the Center contracted directly with the business to provide personal assistant services as a mentor for the individual at his place of work. In Jefferson City, the Regional Center contracted directly with a manufacturing company to provide a modest increase in pay to an existing employee to provide supports to a person with a disability as they became proficient in their job.

Timeline: The Division will choose two Regional Centers where these models have not previously been implemented. In the areas where these strategies will be piloted, we will work closely with providers and the Regional Center to determine efficiency and effectiveness within the next year. Training and information sharing will begin October 2003, with evaluations completed in June 2004.

b. Department of Mental Health Employment Team is researching the feasibility of DMH becoming an Employer Network (EN) under the Social Security Administration's Ticket to Work Program. DMH will determine if some services it currently funds could be reimbursed through the Ticket to Work Program which may allow DMH to improve or expand employment related services for persons who are issued a Ticket to Work.

Timeline: July 15, 2003 – December 31, 2003

9. Family and Consumer Support
(Access, Improved Information)

A. Use of tools such as Developmental Disabilities Resource Center and Share Our Strengths programs

The Missouri Developmental Disability Resource Center serves all Missourian's free of charge as the main source for information on disability and related topics, and provides connections to community supports. The Resource Center is funded with the assistance of the Missouri Planning Council. The Share our Strengths project is a statewide support network of parents, family members, and people with developmental disabilities and professionals who are matched with peer mentors to share experiences, offer emotional support and to network with others. This system has been underutilized.

Beginning immediately, the Division will continue working closely with the Missouri Planning Council for Developmental Disabilities and the University of Missouri – Kansas City, Institute for Human Development to target the use of this system as the main referral point for the citizens of Missouri to become informed and empowered by information relevant to their needs.

The Division will develop a specific procedure for case managers in collaboration with Parent Policy Partners to utilize this resource and educate MRDD staff about these valuable resources. These resources will include publication of 800 phone numbers and links to local resources, as well as Internet links.

Timeline: Currently ongoing

Comments from Focus Group Members:
"Be there when we need you."
"Make it easy for people to know where to go for services, can find services that meet their needs, and can do so in a timely manner."

B. Continued use of Parent Policy Partners

Approximately 5 years ago, in conjunction with the Missouri Consumer Family Directed Support Program, the Division began to contract with parents in the role as Parent Policy Partners (PPPs).

Originally, the PPPs were involved in Parent Training and Person-Centered Planning, as well as participating as members of each regional center's management team as advocates for consumers and families.

OUTCOME

The current program is being reviewed. Each Regional Center Director has been asked to respond to a survey to assist with evaluating the current roles and job responsibilities of the PPPs. It is agreed that their continued participation in each of the regional centers is essential. Once the surveys are complete, the Regional Center Directors and PPPs will collaborate on developing a revised job description.

Timeline: December 1, 2003

10. Study Possibilities of Expansion of Crisis System

(Access, Collaboration)

The Divisions of Comprehensive Psychiatric Services and Alcohol and Drug Abuse currently have contracted for services on a statewide basis whereby consumers have access to 24/7 emergency services, including an 800 number hotline.

The Division of Mental Retardation and Developmental Disabilities will study the possibilities of collaboration between the CPS/ADA system and the MRDD system of Behavior Resource Teams and other crisis and emergency systems.

In addition, the Division will explore the available resources and abilities of local, community-based providers to expand this service on a statewide basis.

Timeline: October 1, 2003 to July 1, 2004.

Comments from Focus Group Members:
"Services must be delivered in a fashion that respects the urgency people feel."
"Immediate response – behavior person who can respond rapidly."

11. Development of Performance Measurements

(Improve Access, Best Practices)

The Department of Mental Health uses performance measures to determine how effective programs are in meeting the needs of consumers and families. However, the performance measures used by the Department will play a critical role during future budget cycles as a result of Senate Bill 299 passed by the General Assembly last session. State agencies must develop and implement a performance-based budgeting system that establishes goals and objectives, provides detailed measures of program and fund performance against attainment of planned outcomes, and provides for program evaluation. The General Assembly will review the performance measures and other outcome data and make decisions on whether programs should be continued or funds redirected to support other more effective programs.

The Division of Mental Retardation and Developmental Disabilities is currently working with the Missouri Results Initiative staff to revise the Division's current performance measures and develop new indicators to more accurately measure the effectiveness of the division's programs. Some examples of the performance measurements that are being developed as they relate to the five DMH values include;

DMH Value #1 - Easy Access
General Public needs easy access to information - Division continues to encourage the use of a resource called the Missouri Developmental Disabilities Resource Center to share information with consumers, families, medical professionals and others free of charge 24-hours a day, seven days a week on the internet.

Performance Measure
Number of times the Missouri Developmental Disabilities Resource Center web site is accessed in a fiscal year. Develop a baseline and project the measure to increase by a certain percentage each year as the site becomes more known as an effective resource.

Consumers and families need easy access to necessary support services - Families and consumers need support services and other generic resources available in their communities to meet their needs.

Performance Measure
The number of days a consumer is placed on waiting lists before receiving the necessary services in accordance with their person centered plan.

DMH Value #2 – Self-Determination

Division implemented Consumer and Family Directed Supports in the late 1990's to allow consumers and family members to self direct their services. The Division continues to move toward self determination by continuing to empower consumers in the decision making process of how they are served and who provides the services. As a result of the System Breakthrough for Excellence a pilot project is being developed to allow consumers the ability to use a "debit card" type system to purchase their support services authorized in their person centered plan from a list of qualified providers. This pilot's goal is to put the consumer and family in control of the funds used to provide their services. This pilot project is currently being reviewed and developed by the Division and may be available to a limited number of consumers during fiscal year 2005.

Performance Measure
The overall satisfaction of consumers self directing their services by using the "debit card" type model will be measured during the pilot to determine if the pilot will go statewide..

These examples and other performance measures will be developed by the Division to track key areas of our service delivery system that we must improve. The Division will continue to work with the Missouri Results Initiative staff and other stakeholders to develop and refine performance measures that accurately reflect the effectiveness of the MRDD programs. These measures will continue to evolve as better data collection systems are developed and the Division builds expertise in the area of performance measurement.

Timeline: Ongoing

Comments from Focus Group Members:
"No waiting lists."
"Services need to be relevant to the time (i.e., respite)"
"Create a system that will accept responsibility of meeting needs, rather than being sent somewhere else for different aspects of treatment."

Approved System-Wide Recommendations
With Proposed Initiatives
Division of MRDD System Breakthrough
August, 2003

System-Wide Recommendations:

A. <u>Improve Access to Services through Collaboration:</u>

1. Improve access to basic community services by collaboration with other agencies;
2. Improve access to specialized services by collaboration with other agencies;
3. Improve access to service coordination;
4. Ensure that services are available;
5. Improve access by streamlining forms and procedures;
6. Improve access by making funding geographically equitable and among consumers with like needs;
7. Improve access by fully implementing the System of Care model.

B. <u>Increase Consumer Choice and Control:</u>

1. Increase consumer choice and control by offering consumers more budget options;
2. Increase consumer choice and control by offering consumers more information to make informed decisions;
3. Increase consumer choice and control by improving the person-centered planning process.

C. <u>Enhance Competence and Information:</u>

1. Enhance competencies of direct care workers;
2. Enhance competencies of service coordinators;
3. Enhance information supports for consumers and families;

Initiative	Goal/Deliverable	Timeline	Initiative Leader
1. Individual Budgets for Consumers (Access, Consumer Choice and Control) (See A.1; A.2; A.5; B.1; B.2; B.3)	**Improved choice and control for people over how their support resources are utilized.** **Enhance quality and satisfaction with services.** **Enhance persons quality of life.**	**Pilot: October, 2004-September 30, 2006**	**Division of MRDD Federal Programs Unit staff**
2. Statewide Rollout of System of Care Model (Access to Specialized Services, Collaboration, Improved Transition for Youth) (See A.1; A.2; A.3; A.7; B.3)	**Full implementation and evaluation of pilot areas and statewide implementation of model, presently for children served by multiple agencies.**	**Evaluation of pilot areas—June, 2004** **Statewide rollout—June, 2006**	**DMH System of Care Teams; Department and Division Director**
3. Standardize Formula for Size and Composition of Caseloads (Access, Specialized Service Coordinators, Reducing Caseloads, Enhanced Competence of Staff) (See A.3; A.4; B.2; C.2; C.3)	**To standardize caseload sizes and review possibilities of specializing caseloads by needs of consumers and families.**	**October, 2003-October, 2004**	**Caseload MAT (Membership of Union representatives and MRDD staff)**
4. Service Coordinator Competencies and Training (Collaboration, Access to Service Coordination, Enhance Competencies) (See A.4; B.2; C.2; C.3)	**Implementation of a statewide training and support system for case managers, using the present Case Management Manual as a base.**	**November, 2003—Analysis and synthesis of data. November, 2004—Initial development and piloting of training.**	**Division of MRDD Training staff; DMH Training staff; Office of Multi-Cultural Affairs**
5. Stabilization Units for Youth and Adults (Access, Collaboration) (See A.4; B.3)	**Give adolescents with behavioral issues an environment that addresses their behavior in a therapeutic environment.** **Stabilize the person for successful transition back into the community or with family members.**	**August, 2003 – Ongoing (Adolescents)** **May, 2004-Ongoing (Adults)**	**Adolescents: Superintendent, Bellefontaine Hab. Center** **Adults: Superintendent, Nevada Hab. Center**

6. Direct Care Worker Competencies and Training (Collaboration, Enhance Competencies and Information) (See A.4; B.2; C.1; C.3)	**Implementation of Workforce Improvement Recommendations**	**October, 2003-October, 2004**	**DMH Director's Office staff, MRDD Training Staff; Office of Multi-Cultural Affairs**
8. Partners in Employment (Access, Collaboration, Consumer Control, Person Centered Planning) (See A.1; A.2; B.2)	**People are prepared to enter supported or competitive employment.** **Assistance with transition from school.**	**September, 2003 – October, 2005**	**Public Entities: Director, Hannibal and Kirksville Regional Centers; Superintendent, Nevada Habilitation Center** **Collaborative Model: Director, Joplin Regional Center** **Missouri Career Network: UMKC Human Development Institute and MRDD Division Director**
9. Family and Consumer Support (Access, Improved Information) (A.1; A.4; A.5; B.3; C.3)	**Use of tools such as Developmental Disabilities Resource Center and Share Our Strengths program.** **Use of tools such as Community Connections through University of Missouri Extension Center.**	**September, 2003-ongoing**	**Missouri Planning Council staff; UMKC Human Development Institute; Division of MRDD Executive Team**
10. Review Possibility of Expansion of Crisis System (Access, Collaboration) (A.1; A.2; A.4; C.3)	**Study feasibility of use of contract presently used by Divisions of Alcohol/Drug Abuse and Psychiatric Services for a 24/7 crisis system.** **Also review existing resources and abilities of provider system.**	**October, 2003-July, 2004.**	**Division of MRDD Executive Team.**

11. Development of Performance Measurements (Access, Best Practices) (See B.2; B.3; C.2; C.3)	**Determine effectiveness of programs serving persons with developmental disabilities.**	**October, 2003-ongoing**	**Division of MRDD staff and staff of Missouri Results Initiative**

SECTION THREE: SEGMENT SPECIFIC RECOMMENDATIONS:

Segment-specific recommendations resulted from work groups responding to the Steering Committee's decision to view the "ideal" public service system for persons with developmental disabilities through the eyes of eight consumer segments:

1. People with Mild and Moderate Disabilities
2. Children's Services
3. People who are Medically Fragile
4. People with Autism
5. People who have Significant or Multiple Disabilities
6. People with Dual Diagnoses
7. People who have High Risk Behavior/Forensic
8. Young Adults Transitioning from High School

The Steering Committee recognized that while the basic needs of consumers most frequently overlap at one or more levels, some consumers benefit from having their needs or circumstances viewed through an alternate lens. For example, some persons among the great number of persons who have "Mild or Moderate Disabilities" would also benefit, in any systems change analysis, from being viewed through an additional lens, such as "Young Adults Transitioning from High School".

Below are listed the recommendations submitted to the Division by the eight work groups that were themselves aligned with the above eight segment specific consumer groups. It is important to note that these eight consumer segments were also the basis for organizing the focus groups that supplied the work groups with feedback.

As discussed at the outset of this draft report, the recommendations which will receive priority attention from the Division are those which surfaced in the segment specific groups which had "system-wide" relevance. For example, the recommendation for individual budgets for consumers came out of several work groups but has system-wide relevance and thus selected as a priority for action.

At the same time, the Division will be constantly reviewing opportunities to respond to the segment specific recommendations. Indeed, for several of these recommendations, activities are, or soon will be, underway. Below, find listed the segment specific recommendations which are linked to a particular segment population and the Division's response to date.

1. Offer services for people who are medically fragile.

Description:
Families have asked that services be available for their children and family members who require medical oversight and attention at a higher level than most other persons served in our system. The services need to be available statewide and be available for short and long-term needs. Services delivered should focus on health maintenance and stabilization of acute/chronic medical issues.

Persons serving this population must be familiar with MRDD syndromes and the medical issues surrounding them.

Benefits:

1. Trained staff will assure that individuals who have disabilities and are considered medically fragile will receive high quality care.
2. The services will need to meet future demands as determined by observation of our current caseload and projections based on new admissions.
3. Services could be available from the Department of Mental Health or through contracts with provider agencies.
4. Families participating in the Lopez waiver may need to have access to this type of service.
5. The Department could utilize current staff to assist the providers to expand community capacity.

Considerations:

1. The location of services will be critical. Families will want services available in their region.
2. The services should meet the Department's current certification guidelines and engage in community membership.
3. Providers of service must have a solid knowledge base of the populations' needs.

Division Response: The Division agrees that there is a need to address medical issues of all persons served by the Division. The Division is working closely with individual families/guardians of persons with complex medical needs to assure that those needs are addressed. Services are currently being provided through community resources and in habilitation centers throughout the State. This is an area the Division will continue to develop."

2. Specialized Service Coordinators for Autism

Description

Specialized service coordinators who are receiving ongoing competency-based, hands-on training in autism will support persons with autism and their families. Approximately 9% of the persons we serve are individuals with autism. Under this recommendation, autism would become a specialization for service coordinators and the number of designed specialized service coordinators would be in sync with the current and growing need.

Benefits

1. Parents will receive needed information and be empowered to make decisions;
2. Relationships among families, service coordinators and providers will be improved because all will understand the unique characteristics of autism;
3. People who have autism and their families will receive more appropriate services through the development of autism-specific, person-centered plans;

Considerations

1. Funding;
2. Shifting of service coordinators and work loads;
3. Maintaining specialization/competencies;
4. Geography.

Division Response: As part of #8 in the initiative section above, the training package also includes case managers, which may be expanded for "specialization" as the project was originally designed.

3. Transition system for youth entering adulthood

Description:
Identify when youths turn 14, and develop "ticklers" in the system so that the planning for transition can begin in a timely manner. When the planning begins, all agencies will be involved, but only one plan will be produced, and only one service coordinator will be assigned as the main contact for the youth.

Benefits;

1. Early identification for consumers needing transition planning;
2. Prevents consumers from falling through the cracks of the system;
3. Allows more time for consumers to explore and act on career and lifestyle choices;
4. Elimination of multiple planning meetings;
5. Reduces duplication of information gathering and testing / assessment;
6. Provides everyone with the same information;
7. Enhances the knowledge of available supports and services by having all experts at the table;
8. Makes the system easier for the family to navigate;
9. Assures that the consumer is an active participant in the planning process and that their needs are met according to their wishes;
10. Provides a better process for the pooling of agency resources.

Considerations

1. Outreach to all kids, as many are not in the system;
2. Sensitivity to the timelines and regulations challenging school systems;
3. Multiple agency policies will need to be changed;
4. Health Insurance Portability and Accountability Act (HIPAA);
5. May require legislative action;
6. Agency cooperation.

Division Response: The Division agrees that transition planning is a high priority, especially for young persons going from school-age to adulthood. This transition will be a focus of the Regional Centers and service coordinators, including the statewide rollout of the system of care model, where multiple agencies work with the family in planning for services for young persons. In addition, the Division's representative on the departmental Employment Team will ensure the next DMH Employment Plan includes goals related to transition planning.

Some of the employment initiatives described in "1" above will target some individuals transitioning from high-school as well. Once the pilots are fully developed, a tracking system for early identification will be a component of the employment initiative.

4. Develop age-appropriate resources and treatment programs to include stabilization "units" and crisis response systems. Include Behavior Resource knowledge in the training of crisis response team members.

Description:
Resources should be appropriate for the age of our clients, many being children. By having a crisis response plan and team in place, consumers will be able to get what they need in a timely manner. The teams don't necessarily have to be at each regional center. (e.g., they could follow the National Transportation Safety Board model – go to the accident). Access to state and federal funding will be a critical piece of the structure of this system.

Benefits

1. The framework already exists;
2. Would ameliorate many of the observed barriers and criticisms levied against the current system;
3. 24 / 7 assistance would be available for consumers and families.

Considerations

1. Crisis response teams should be comprised of experienced staff;
2. Might have to consider a shift in case loads in order to accommodate the needs of persons in crisis and size of caseload that these staff can carry.

Division Response: This issue is addressed in the initiative called "Stabilization Units" which are being piloted, one in St. Louis (Bellefontaine) and one in Nevada (adults).

5. Develop "Best Practices" model for Dually Diagnosed consumers that meets their individual needs.

Description:
See how other states and facilities deal with Dually Diagnosed Consumers, and take note of what works. When something is impressive, benchmark it and strive to copy it.

Benefits

1. Families would know how to communicate with physicians and case coordinators;
2. Education for individuals about their situation, their diagnosis, treatment and habilitation options;
3. Potential to become the standard by which other states benchmark themselves.

Considerations

1. Potential to benchmark unattainable goals;
2. Potential to benchmark goals that are already reached.

Division Response: The Division feels strongly that education, information and collaboration are keys to the treatment and habilitation of persons who are dually diagnosed. Further collaboration through the System of Care rollout, and additional information available to families/guardians and providers is crucial. Additionally, the system of care initiative will address several of the concerns regarding the obtainment of services for individuals with co-existing disorders.

6. Incorporate behavior risk screening at the regional centers after eligibility is determined.

Description:
Develop a non-intrusive way to screen for behavioral risks after eligibility determination of High Risk / Forensic consumers.

Benefits

1. Identifies the consumer at risk to refer to the Behavioral Resource Team / Crisis Response Team;
2. The consumer at risk is able to receive help prior to the situation becoming a crisis;
3. Consumer receives services faster;
4. Prevent / reduce admissions to acute settings;
5. Reduce family pressure.

Considerations

1. Consider consolidating screenings at intake to avoid duplication;
2. Staff training for the screening tool could be expensive and time-consuming.

Division Response: This recommendation will be further considered by the Division.

7. Modify service plan to incorporate "future" section that forecasts and plans for the long term. Develop a service plan (personal plan) that includes a section for future or long range needs which enables self-determination and flexible planning based on the individual's "lifestyle needs" rather than a "menu" or available programs or services.

Description:
Planning will be done based on the consumer's "lifestyle needs," rather than a "menu" of available programs or services.

Benefits

1. Individual needs met more timely with an appropriate response;
2. Should avert crises;
3. Truly individualized service based on need now and in the future;
4. Offers more choices, and addresses future needs of the family.

Considerations

1. Budgeting more difficult;
2. Possibly more paperwork.

Division Response: The Quality Framework Team (a statewide group of quality assurance staff in all regional centers and habilitation centers) is working on this issue presently and will be implementing a pilot very soon.

8. Promote awareness and use of limited guardianship and alternatives to guardianship.

Description:
There are many options surrounding guardianship, but most people only know that you either give it up or you keep it. Partnerships will be formed with other agencies and advocacy groups to promote options.

Benefits

1. More ability for the consumer to control his / her own life;
2. More ability for the consumer to be involved in community;
3. Promotes self-determination;
4. Consumers and families would know all of their options;
5. Consumers would know the proper timing to revoke guardianship if that's what they choose.

Considerations

1. May take time to roll out;
2. May be difficult to get groups/agencies to work together;
3. May be persons who oppose this idea;
4. Service coordinators will need more information.

Division Response: The Division will work with the Missouri Planning Council and other stakeholders in partnership to advance the use of limited guardianships, as appropriate, and promote options for people.

CONCLUSIONS AND NEXT STEPS:

The decision to redesign the **System of Service** by looking through the eyes of the consumers forced the Steering Committee, and then the workgroups, to segment those consumers into eight definable groups:

1. Mild and Moderate Disabilities
2. Children's Services
3. Individuals who are Medically Fragile
4. Individuals with Autism
5. Significant/Multiple Disabilities
6. Individuals who have Dual Diagnosis
7. Individuals who are High Risk/Forensic
8. Young Adults Transitioning from High School

By going throughout the state conducting focus groups with over 600 individuals that fall into the above categories, the work groups were able to identify the wants and needs of MRDD's consumers. This information, along with team-requested data, helped the teams to determine where the gaps in service delivery are occurring. The recommendations of each team were presented with the goal to close the identified gaps and meet future needs.

Upon presentation of the team recommendations, it became apparent that there were common themes cutting across consumer segments. Once it was determined which themes would have the largest impact on multiple components of the entire service delivery system, Steering Committee members identified how to achieve the desired results.

Concurrently, recommendations remained which were specific to each consumer segment after the common themes were addressed. In contrast to the common themes, these are recommendations that will improve the quality of service for one or two segments only. The consumer segment specific recommendations are addressed by some of the system-wide recommendations. The report identifies initiatives that address more than one recommendation.

The report you have just reviewed is not the end of this project. On the contrary, this project is just beginning. In order to validate the tremendous efforts put forth by so many people from all sides of Missouri's mental health industry, specific "next steps" will be followed to ensure implementation and increase in the quality of life for persons with developmental disabilities, their families and contract providers. The "next steps" are below:

1. Steering Committee approval of action plans;
2. Mental Health Commission Review and approval of action plans;
3. Public Comment;
4. Finalized Project plan;
5. Implementation phase;
6. Regular review of progress;
7. Success Measurement of development and review.

The Missouri Results Initiative staff has recommended that the highest priority be the implementation of the three system-wide recommendations, as their successful implementation will

have the most positive and pervasive impact on persons with developmental disabilities, their families and contract providers. The development of the segment-specific action plans and other recommendations that are a part of the teams' suggestions will determine the Division's next steps within the System Breakthrough.

Now the future of MRDD's System of Service is in the hands of those responsible for implementation – persons with developmental disabilities and their families; advocates; the Division of Mental Retardation and Developmental Disabilities staff; other state agencies; and contract providers. It is going to take effort from stakeholders to realize needed changes and all must understand that the changes recommended in this report will not be realized overnight. Most importantly, it will take a consistent, steady effort to always keep the consumer's expectations of our sites and as our guide to continuous improvement in effective service delivery.

Appendix A

TEAM CHARTER:

Project: Quality Outcomes for Persons with Developmental Disabilities
Sponsor: Dr. Anne Deaton, Director, Division of Mental Retardation and Developmental Disabilities

The Challenge:

1. The Division of MRDD is responsible for ensuring that today's support system for persons with developmental disabilities is effectively meeting the needs of eligible persons and their families in a manner that maximizes accessibility and availability of appropriate services, informed choice, community integration, health and consumer safety.
2. It is currently difficult to assess if the Division and the public service system are meeting the needs of consumers and families, as well as how we plan to meet the needs of consumers five years from now.
3. The Division of MRDD must also project the needs of tomorrow's (5-10 years) consumers and families and develop a long-range plan to address the future needs of persons with developmental disabilities in Missouri.
4. The Division of MRDD must prepare the public and private sectors for projected changes in the population of persons to be served.

Desired Outcomes:

1 Identification of current consumer groups and their desired care outcomes.
2. Identification of gaps in service delivery (what do they want that we currently don't provide)
3. Closing the above gaps.
4. Identification of socio-demographic trends that predict changes in the consumer profile over the next decade.
5. A financially feasible plan to effectively meet the changing consumer outcomes in the next decade.
6. A prioritized plan of proaction—what needs to happen first, etc.

Undesired Outcomes:

1. Adverse impact to persons currently receiving services.
2. Cost increases for those persons served that prevent other eligible persons from receiving service (diminished service system capacity).
3. Cost shifts from or to other responsible agencies.
4. Promises of expansion of programs and services without a plan for funding.
5. Divisiveness among various stakeholder groups.
6. Falsely raising consumer expectations of future services.
7. Diminished provider capacity, thus diminished provider choice.
8. Any weakening of consumer driven/person centered system.
9. Narrow choices of services for consumers.
10. Any recommendations contrary to Missouri Quality Outcomes document.

Boundaries:

1. Infrastructure, policy and law changes are open for analysis.
2. Must not hinder Division of MRDD from a service delivery system that supports a diverse population of persons within a framework marked by person-centeredness, self determination, safety, most integrated living arrangement, and cost-effectiveness.
3. Recommendations must be aligned with and support the Department of Mental Health's vision:

Missourians shall be free to live their lives and pursue their dreams beyond the limitations of mental illness, developmental disabilities and alcohol and other drug abuse.

Appendix B

STEERING COMMITTEE MEMBERSHIP:

Co-Chairs:

Joann Noll, President
Missouri Planning Council

Bob Story, Parent
Higginsville Parents Association

CONSUMERS/PARENTS/ADVOCATES:	
Missouri Planning Council for Developmental Disabilities	Joann Noll Co-Chair
Parent	Bob Story Co-Chair
Department of Mental Health Mental Health Commission	Alan Baumgartner, Chair
Regional Advisory Councils	Jeff Corbin, Staff Gateway Regional Council, St. Louis
People First	Anita Carroll, Kansas City
Association of Retarded Citizens Of Missouri	Bert Sterbenz, Vice President St. Louis
Habilitation Center Parents Associations	Elizabeth Hucke, Parent St. Louis
Parent/Family Member	Patti Johns, Parent/RAC Member St. Louis
Missouri Alliance for Individuals with Developmental Disabilities (MOAIDD)	Gary Stevens, President
Personal Independence Commission (PIC)	Kirsten Dunham, Co-Chair Personal Independence Commission
DD Resource Center—UMKC (DDRC)	Dr. Carl Calkins
PROVIDERS:	
Missouri Association of Rehabilitation Facilities (MARF)	Bruce Scott Kansas City
Direct Support Professionals	Don Carrick Northwest Missouri
Missouri American Network of Community Options (MOANCOR)	Marilyn Nolan Springfield
FUNDING PARTNERS	
Missouri Association of County Disabilities Services (MACDDS)	Janice Tillman Platte County
OTHER STATE AGENCIES:	
Department of Health and Senior Services	Rita Summers, Senior Services Lois Heldenbrand, Dept. of Health

Department of Elementary and Secondary Education	Melodie Friedebach, Asst. Commissioner Special Education
Division of Family Services	Keith Krueger, Children's Services
DEPARTMENT OF MENTAL HEALTH STAFF:	
Department of Mental Health Office of Multicultural Affairs	Derrick Willis
Department of Mental Health Medical Director	Dr. Joseph Parks
Department of Mental Health Division of Comprehensive Psychiatric Services	Diane McFarland Director
Department of Mental Health Division of Mental Retardation and Developmental Disabilities	District Deputies: Richard Strecker, East Jerry Clubbs, East Gail Clair, North Kent Stalder, South
LEGISLATORS:	
State Senators	Senator Steve Stoll, St. Louis
	Senator Charlie Shields, St. Joseph
State Representatives	Representative Vicky Riback-Wilson, Columbia
	Representative Roy Holand, Springfield

APPENDIX C

CONSUMER FOCUSED PROCESS SUPPORTING PROJECT (An Outline of Work Process):

1. **Developed the Team Charter-** The team charter, developed by Dr. Deaton, Project Sponsor, defines the charge and the parameters of this project.

2. **Steering Committee Formed** – A 30-member steering committee was formed to provide guidance throughout the process and make final recommendations to Dr. Deaton. The Steering Committee first met in December, 2002 to approve the charter, and to divide those persons served by the public DD system into groups having distinct characteristics, unique needs and different expectations.

3. **Consumer Segment Work Groups** – Multi-disciplinary teams of eight (8) to twelve (12) people were recruited for each segment, and each team was given the charge of gathering statewide input to develop recommendations. The recommendations outlined in this report are a direct response to consumer input. The eight work groups:
    A. Collected and analyzed data;
    B. Conducted over seven (70) focus groups, interacting with over at least 600 participants;
    C. Determined consumers expectations: Three things consumers care about regardless of product
        1. Outcomes: the results achieved by using the product;
        2. Attributes: the characteristics of the product;
        3. Features: how the outcomes and attributes come to life

    For example, one focus group determined:
        1. Outcome: Productive, happy, independent consumers with self esteem;
        2. Attributes: The system of service will be accessible, timely, consumer friendly and person-centered;
        3. Features: Web-based information, on-line password accounts, fewer forms, consumer control

    D. Used focus group information in developing recommendations that were prioritized and filtered by the teams;

4. **Steering Committee Approval:** Following presentations by each work group, the Steering Committee prioritized the recommendations to develop a Division of MRDD system-wide plan that was submitted to Dr. Deaton for final approval and response. The Steering Committee used Relationship Diagrams to identify the primary goals for the Division. The primary goals identified by the Steering Committee are the three system-wide recommendations to improve access to services through community collaboration, increase consumer choice and control, and enhance staff competencies and information (see page 5).

5. **Implementation Plan Development:** A series of deliverables, as well as success measures, will be tied to the implementation plan.

6. **Review:** Status updates from the persons responsible for implementation plan deliverables are scheduled when the plan is developed.

7. **Determine Consumers' Prioritized Expectations:** Consumers and stakeholders will be asked annually about the system's effectiveness. By creating a continuous cycle of improvement through the consumer's eyes, the Division of MRDD can best meet the individual needs of persons with developmental disabilities and their families.

Appendix D

SYSTEM-WIDE RECOMMENDATIONS:

Upon reviewing the work of each team, it is interesting to note that research found very few people complaining about the quality of service received through the Division of MRDD. The primary problem seems to occur between identification of a problem and actually becoming eligible for and beginning to receive services; that is, the information acquisition, the intake, the assessment and planning processes involved in accessing the Division's quality services. The recommendations point toward a number of system-wide issues; "system-wide" in the sense that work group members realized that effective response to certain issues had immediate repercussions for improvements in service delivery and/or quality service for other segments. Both system wide and segment specific issues will be addressed. However, the Division of MRDD will begin with the system-wide recommendations, so that immediate improvements that are widespread and far-reaching can be implemented on timelines that will be evaluated and tracked.

Common Themes:

Based on the eight segment specific team's recommendations, the following common themes are present:

1. Improve access to information
2. Make funding equitable geographically and among consumers with like needs
3. Better collaboration with community to provide services
4. Give consumers choice/control over resources
5. Identify risk factors earlier in children
6. Reduce the administrative burden (for staff and consumers) to get services
7. Improve skills/competency through training and development for staff

Essentially, the Division of MRDD can improve any of the above referenced common themes and life will be better for persons served, regardless of any consumer segment they might fit into. These common themes then also were reduced to the top three system-wide issues, as addressed below:

1. Improve Access to Services;
2. Increase Consumer Choice and Control;
3. Enhance Competence and Information

A. IMPROVE ACCESS TO SERVICES:

1. Improve access to basic community services by collaboration with other agencies:
   a. Work with community coalitions to expand local housing, employment, recreation and transportation opportunities.

2. Improve access to specialized services by collaboration with other agencies:
   a. Make crisis response services available statewide;
   b. Make stabilization beds available at each habilitation center;
   c. Extend specialized services from the habilitation centers into the community;

d. Expand and improve residential services for persons with medical fragility;
e. Expand and improve services for persons with autism;
f. Expand and improve services for persons with co-occurring disorders;
g. Conduct behavioral risk screening (when indicated) at regional centers
h. Improve early identification of children at risk by collaboration with school and other human service agencies.
i. Explore the feasibility of individuals having a single plan when multiple agencies are involved and blending funding across state agencies.

3. Improve access to service coordination:
   a. Return calls and e-mails in a timely manner;
   b. Assign specialized service coordinators as appropriate;
   c. Investigate using a standardized formula statewide to assign caseloads;
   d. Reduce caseloads (e.g., by expanding county agreements and agreements with other agencies)

4. Ensure that services are available:
   a. Establish a feedback loop from consumers (and service coordinators) to report service shortages;
   b. Analyze gaps by county;
   c. Develop new providers;
   d. Study and replicate best practices.

5. Improve access by streamlining forms and procedures:
   a. Work with other agencies to develop cross-agency applications;
   b. Develop cross-agency Person Centered Planning budgeting;
   c. Work toward one Person Centered Plan across agencies (the person has a single plan, versus the agencies having a plan for the person);
   d. Reduce or shorten Division of MRDD forms;
   e. Simply Division of MRDD procedures (programmatic and financial) for consumers and providers.

6. Improve access by making funding equitable geographically and among consumers with like needs:
   a. Continued use of the Division approved Utilization Review process to match need and individual allocation;
   b. Develop formula for future county and regional allocation of funds;

7. Improve access by fully implementing the System of Care model, presently used on a pilot basis in several areas of the state, which requires agencies to work together as a team to meet the needs of children and families, regardless of where the children "enter the system".

B. INCREASE CONSUMER CHOICE AND CONTROL:

1. Increase consumer choice and control by offering consumers more budget options:
   a. Investigate instruments that assess, match, and track consumer need with individual allocation amount. Modify individual budgets to allow consumers to control their own service purchases within the parameters of their own Person Centered Plan.

b. Research development of a "debit card system" to facilitate payment to providers;
c. Modify and improve the Fiscal Intermediary System, whereby a family can hire their own workers and have paperwork done through this process;
d. Investigate Internet Password Accounts (Family Account banking) where consumers can access their plans and budgets, showing expenditures to date.

2. Increase consumer choice and control by offering consumers more information to make informed decisions:
   a. Consumer Guide website (some printed copies) to house information below;
   b. Consumer reports on services and programs:
      1. Licensure and Certification reports (from Office of Quality Management);
      2. Investigate having an online page which has a moderated consumer feedback page;
      3. Missouri Association of Individuals with Developmental Disabilities (MOAIDD) reports;
      4. Division of MRDD Quality Assurance reports;
      5. Commission on Accreditation of Rehabilitation Facilities (CARF) and other licensing organization reports.
   c. Develop methods to compare system performance with industry benchmarks and best practices;
   d. Make sure consumers/families KNOW about all resources and options available
   e. Provide consumers with provider rates and quality information (licensure reports, etc) so they can decide where their dollars are most effectively spent.

3. Increase consumer choice and control by improving the person-centered planning process:
   a. Integrate long-term planning (futures planning) into the person centered planning process;
   b. Add prompts (ticklers) into the planning and service coordination process for important transition ages (3, 5, 14), etc.;
   c. Address alternatives to full guardianship early in the process;
   d. Actively involve the persons who know the consumer best, including direct care staff, where that may be applicable.

C. ENHANCE COMPETENCE AND INFORMATION:

1. Enhance competencies of direct care workers:
   a. Establish a set of core competencies;
   b. Develop competency-based training;
   c. Develop direct care worker certification program;
   d. Tie direct care pay to competency and certification.

2. Enhance competencies of service coordinators:
   a. All service coordinators will receive consumer satisfaction training in addition to their core training;
   b. All regions will have service coordinators who have specialized service training (autism, co-occurring disorders, deafness, medical issues) in needed areas;
   c. Hire bi-lingual service coordinators in high need areas;
   d. All service coordinators will receive training in cultural competency.

3. Enhance information supports for consumers and families:
    a. Assist families to acquire needed training;
    b. Support statewide mentoring and family support programs;
    c. Make available multiple means of communication (e-mail, phone, mail, visit);
    d. Make plans, budgets, newsletters, questionnaires, etc, accessible via the Internet;
    e. Organize, coordinate and increase access to information via the Internet:
        1. Support consolidation of information through one portal (e.g., Missouri Developmental Disabilities Resource Center at University of Missouri Kansas City);
        2. Support consolidation of directory information through one portal (e.g. Community Connections through University of Missouri, Columbia). These could be linked.
    f. Make material available on CD in other languages

APPENDIX E

SEGMENT SPECIFIC RECOMMENDATIONS:

As referenced earlier in the report, the work groups broke up into eight segment-specific groups. Through this process, eight additional segment-specific recommendations were made (second in priority to the system-wide recommendations). These recommendations are:

1. Offer services for people who are medically fragile.

Description:
Families have asked that services be available for their children and family members who require medical oversight and attention at a higher level than most other persons served in our system. The services need to be available statewide and be available for short and long-term needs. Staff will require additional and specialized training to ensure health needs are met.

Benefits:

1. Dedicated staff will assure that individuals who have disabilities and are considered medically fragile will receive high quality care.
2. The services will need to meet the demand as determined by observation of our current caseload and projections based on new admissions.
3. Services could be available from the Department of Mental Health or through contracts with provider agencies.
4. Families participating in the Lopez waiver may need to have access to this type of service.

Considerations:

1. The location of services will be critical. Families will want services available in their region.
2. The services should meet the Department's current certification guidelines and engage in community membership.

2. Specialized Service Coordinators for Autism

Description
Specialized service coordinators who are receiving ongoing competency-based, hands-on training in autism will support persons with autism and their families. Approximately 9% of the persons we serve are individuals with autism. Under this recommendation, autism would become a specialization for service coordinators and the number of designed specialized service coordinators would be in sync with the current and growing need.

Benefits

1. Parents will receive needed information and be empowered to make decisions;

2. Relationships among families, service coordinators and providers will be improved because all will understand the unique characteristics of autism;
3. People who have autism and their families will receive more appropriate services through the development of autism-specific, person-centered plans

Considerations
1. Funding;
2. Shifting of service coordinators and work loads;
3. Maintaining specialization/competencies;
4. Geography.

3. Transition system for youth entering adulthood

Description:
Identify when youths turn 14, and develop "ticklers" in the system so that the planning for transition can begin in a timely manner. When the planning begins, all agencies will be involved, but only one plan will be produced, and only one service coordinator will be assigned as the main contact for the youth.

Benefits:
1. Early identification for consumers needing transition planning;
2. Prevents consumers from falling through the cracks of the system;
3. Allows more time for consumers to explore and act on career and lifestyle choices;
4. Elimination of multiple planning meetings;
5. Reduces duplication of information gathering and testing / assessment;
6. Provides everyone with the same information;
7. Enhances the knowledge of available supports and services by having all experts at the table;
8. Makes the system easier for the family to navigate;
9. Assures that the consumer is an active participant in the planning process and that their needs are met according to their wishes;
10. Provides a better process for the pooling of agency resources.

Considerations
1. Outreach to all kids, as many are not in the system;
2. Sensitivity to the timelines and regulations challenging school systems;
3. Multiple agency policies will need to be changed;
4. Health Insurance Portability and Accountability Act (HIPAA);
5. May require legislative action
6. Agency cooperation

4. Develop age-appropriate resources and treatment programs to include stabilization "units" and crisis response systems. Include Behavior Resource knowledge in the training of crisis response team members.

Description:
Resources should be appropriate for the age of our clients, many being children. By having a crisis response plan and team in place, consumers will be able to get what they need in a timely

manner. The teams don't necessarily have to be at each regional center. (e.g., they could follow the National Transportation Safety Board model – go to the accident). Access to state and federal funding will be a critical piece of the structure of this system.

Benefits

1. The framework already exists;
2. Would ameliorate many of the observed barriers and criticisms levied against the current system;
3. 24 / 7 assistance would be available for consumers and families.

Considerations

1. Crisis response teams should be comprised of experienced staff;
2. Might have to consider a shift in case loads in order to accommodate the needs of persons in crisis and size of caseload that these staff can carry

5. Develop "Best Practices" model for Dually Diagnosed consumers that meets their individual needs.

Description:
See how other states and facilities deal with Dually Diagnosed Consumers, and take note of what works. When something is impressive, benchmark it and strive to copy it.

Benefits

1. Families would know how to communicate with physicians and case coordinators;
2. Education for individuals about their situation, their diagnosis, treatment and habilitation options
3. Potential to become the standard by which other states benchmark themselves

Considerations

1. Potential to benchmark unattainable goals;
2. Potential to benchmark goals that are already reached.

6. Incorporate behavior risk screening at the regional centers after eligibility is determined.

Description:
Develop a non-intrusive way to screen for behavioral risks after eligibility determination of High Risk / Forensic consumers.

Benefits

1. Identifies the consumer at risk to refer to the Behavioral Resource Team / Crisis Response Team;
2. The consumer at risk is able to receive help prior to the situation becoming a crisis;
3. Consumer receives services faster;
4. Prevent / reduce admissions to acute settings;
5. Reduce family pressure.

Considerations

1. Consider consolidating screenings at intake to avoid duplication;
2. Staff training for the screening tool could be expensive and time-consuming.

7. Modify service plan to incorporate "future" section that forecasts and plans for the long term. Develop a service plan (personal plan) that includes a section for future or long range needs which enables self-determination and flexible planning based on the individual's "lifestyle needs" rather than a "menu" or available programs or services.

Description:
Planning will be done based on the consumer's "lifestyle needs," rather than a "menu" of available programs or services.

Benefits
1. Individual needs met more timely with an appropriate response;
2. Should avert crises;
3. Truly individualized service based on need now and in the future
4. Offers more choices, and addresses future needs of the family.

Considerations
1. Budgeting more difficult;
2. Possibly more paperwork.

8. Promote awareness and use of limited guardianship and alternatives to guardianship.

Description:
There are many options surrounding guardianship, but most people only know that you either give it up or you keep it. Partnerships will be formed with other agencies and advocacy groups to promote options.

Benefits
1. More ability for the consumer to control his / her own life;
2. More ability for the consumer to be involved in community;
3. Promotes self-determination;
4. Consumers and families would know all of their options;
5. Consumers would know the proper timing to revoke guardianship if that's what they choose.

Considerations
1. May take time to roll out;
2. May be difficult to get groups/agencies to work together;
3. May be persons who oppose this idea;
4. Service coordinators will need more information.

CONSUMER SEGMENTS:

The Steering Committee chose to view the "ideal" public service system for persons with developmental disabilities through the eyes of eight consumer segments.

A breakdown of each consumer segment is attached in the Appendix. Team members, the segment's priority attributes and team recommendations are summarized in the Appendix.

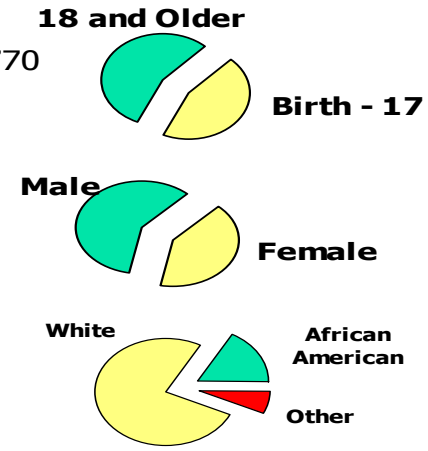
1. **People with Mild & Moderate Disabilities**
2. **Children's Services**
3. **People who are Medically Fragile**
4. **People with Autism**
5. **People who have Significant or Multiple Disabilities**
6. **People with Dual Diagnoses**
7. **People who have High Risk Behavior / Forensic**
8. **Young Adults Transitioning From High School**

Appendix F

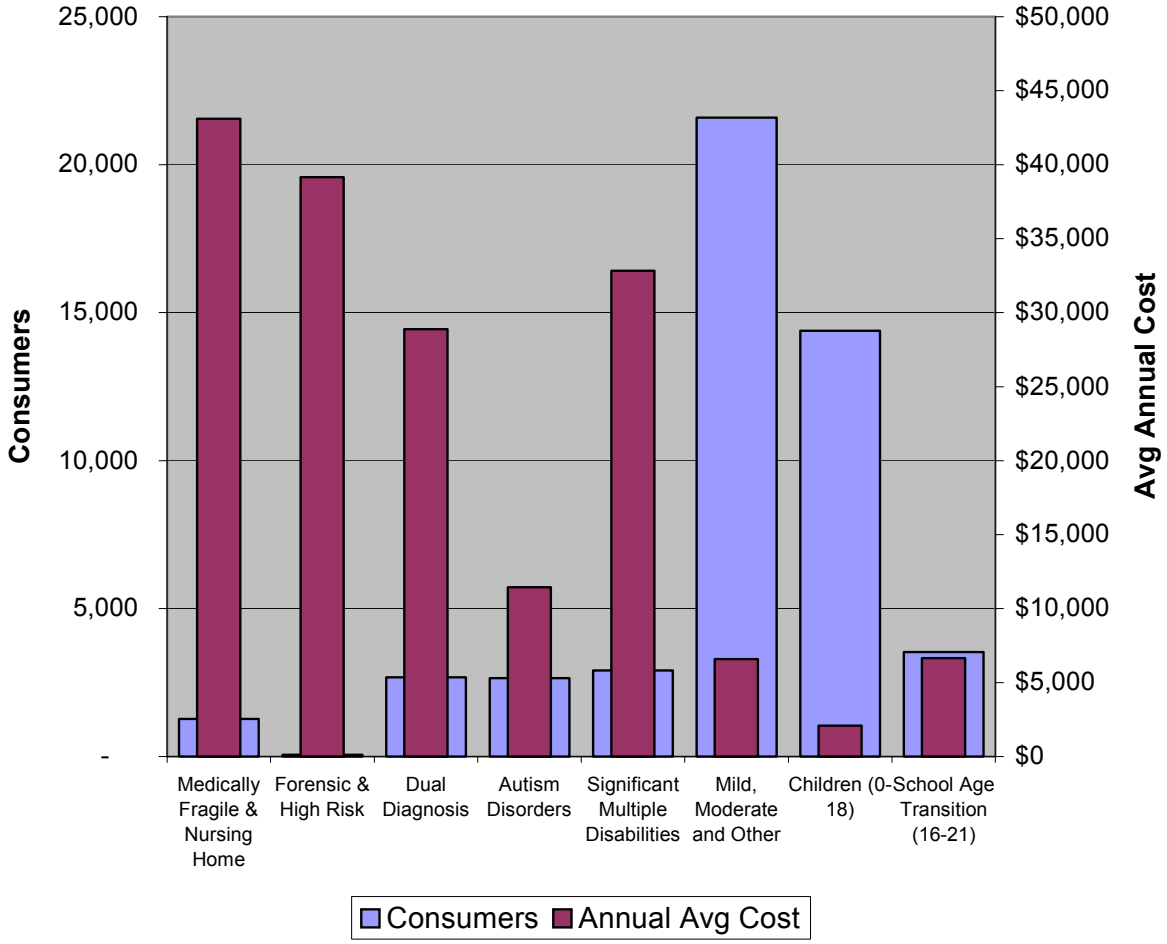
MRDD Consumer Demographics

- Age
  - Birth through 17 years – 13,770
  - 18 years and older – 17,382
- Gender
  - Female – 12,533
  - Male – 18,619
- Race
  - White – 23,839
  - African American – 5,197
  - Other – 2,116

Information compiled July 2002



Division of MRDD
Cost of Services by Consumer Segments



Based on FY 02 data*

Consumer Segments	Number of Consumers	Cost of Services (Note 1)	Average Annual Cost Per Consumer
Medically Fragile & Nursing Home	1,274	$54,916,594	$43,106
Forensic & High Risk	62	$2,427,009	$39,145
Dual Diagnosis	2,678	$77,320,760	$28,873
Autism Disorders	2,648	$30,308,701	$11,446
Significant Multiple Disabilities	2,903	$95,288,636	$32,824
Mild, Moderate and Other	21,585	$142,026,467	$6,580
Children (0-18) {Note 2}	14,386	$30,034,726	$2,088
School Age Transition (16-21) {Note 2}	3,532	$23,471,628	$6,645

Note 1 – Cost includes 100% of the service costs which includes Federal match, General Revenue, private pay and third party benefits.
Note 2 – Number of consumers and $'s are duplicated in other consumer segments.

* The division will need to devise a tracking method to compare future data with the FY02 benchmarks.

Special Issue:
FY'04 Caseload Growth Funds

The Division was appropriated "Caseload Growth" funds in the amount of $5.0 million in Fiscal Year 2004. Funds will be used to help address the growing number of Medicaid eligible consumers on waiting lists for services.

- July 2004 funds were allocated to serve 203 consumers with the highest "utilization review" score.
- 88 consumers have been removed from the waiting lists.
- Regional Center staff continue to work with another 115 consumers and families to identify a service provider.
- The Division will evaluate the cost of these services and determine if additional consumers can be served with the "Caseload Growth" funds.

Special Issue:
Community Support Waiver – Update

The Division received approval for the Community Support Waiver on July 1, 2003. Regional Centers have been authorizing waiver slots for individuals eligible for this new waiver.

To be eligible;

- Consumers must meet the same ICF/MR level of care as the current MRDD Comprehensive Waiver.
- Total cost of waiver services they are determined to need cannot exceed $20,000 annually.
- Consumer's needs must be met by using non-residential support services.
- The Division will continue to "refinance" services funded with General Revenue by using this new waiver.

Special Issue:
Division of MRDD Waiting List

Department of Mental Health
Division of Mental Retardation and Developmental Disabilities
Priority Services Report – August 4, 2003

Note: Not all individuals are Medicaid eligible.

Regional Center	Residential		
	Priority I	Priority II	Total
Albany RC	1	7	8
Kansas City RC	56	107	163
Joplin RC	10	12	22
Springfield RC	5	53	58
Poplar Bluff RC	8	19	27
Sikeston RC	3	37	40
Kirksville RC	8	6	14
Hannibal RC	5	16	21
Rolla RC	1	12	13
Central MO RC (Columbia)	10	71	81
St. Louis RC	52	142	194
Statewide Total	159	482	641

Priority I Consumer is in need of emergency residential services and supports and may be receiving temporary services until a more permanent service can be found. Consumer's health, safety, or quality or life is compromised by less than adequate living arrangements or supports. Temporary supports in place until a permanent arrangement is found or developed.

Priority II Family support is no longer available or primary caregiver is in poor health or elderly.

Special Issue:

Structure of the Division's Future Service Delivery System

- *The Division of MRDD has consolidated administrative and management positions in state-run facilities;*
- *The Division will continue to review and study the infrastructure of the public service system for persons with developmental disabilities;*
- *This will be ongoing work in cooperation with stakeholders, including the Missouri Planning Council, the Regional Councils, and consumer and advocacy groups;*
- *The Division is committed to continue to support all choices of residence for persons with developmental disabilities and their families.*

Special Issue:

Reaching Out to All Consumer Demographic Groups

- Each of the System Breakthrough for Excellence segment groups included invitations to or discussions with consumers or groups that represented the diversity of the people we support, and those agencies that are a part of the system of care. It was the Division's intent that each step of the consumer satisfaction process included a broad cross-section of people who are touched or who work within the system of care. During the focus group phase, additional sessions were hosted in urban areas in an attempt to include more feedback from those particular individuals.
- As we implement success measures and progress reviews, the Division will strengthen its efforts to reach and include people that are more fully representative of the consumer demographics as reflected in Appendix "F".
- Those efforts will include a request for assistance in this process from the Regional Advisory Councils, and the Office of Cultural Diversity in the Department of Mental Health.

Appendix G

ACKNOWLEDGEMENTS OF CONTRIBUTORS:

This document is the product of innumerable hours of work by many people, including persons with developmental disabilities, family members, Division of MRDD staff, staff of the Missouri Results Initiative (MRI), the Regional Councils, and other state agencies, among a few. The Division would like to formally thank those listed below, and all those who we may formally miss listing, but to whom we are indebted. The commitment of time, expertise and experience, in these short timelines, was truly appreciated and provided an amazing process to observe.

Team Sponsor:	**Dr. Anne Deaton, Division Director**
Co-Chairs:	**Joann Noll, Bob Story**
Family Members And Advocates:	**All those who participated, across the State, in the work group sessions, as work group Co-Chairs or members, and those that sent written comments.**
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Division Liaison:	**Julia Kaufmann**
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Other Facilitators:

Facilitator	**Jennifer McKinney, Missouri Department of Economic Development**
Facilitator	**Ronda Anderson, Missouri Department of Economic Development**
Facilitator	**Gloria Andrews, Missouri Department of Economic Development**
Facilitator	**Robert Crouch, Missouri Department of Labor and Industrial Relations**
Facilitator	**Lisa Sone, Vocational Rehabilitation**
Facilitator	**Rebecca Geyer, Transportation**